

Good afternoon-

I am writing with my support for this bill.

I have a unique perspective as a parent of a now adult with a rare disorder (HCU), physical therapist and parent representative on the State of Michigan NBS Advisory Committee for nearly 20 years. I have some recommendations for you as you work through the details of this bill. It is my hope that you are as successful as possible in running this council and have the most comprehensive panel of stakeholders to bring the best level of advocacy to this group of individuals.

I was able to attend today's meeting and noted several questions that arose regarding funding, benchmarks and others that the NBS advisory committee has handled in the past.

Please continue to reach out to me for specific recommendations based on the best practices and barriers to success that I have observed through my experience with a similar panel at NBS. I am hopeful that establishing this council will bring great positive changes to the rare disorder community in Michigan. Thank you for your work.

Therese Waters, PT